

National End of Life Care Programme

Improving end of life care

The route to success
in end of life care – achieving
quality for lesbian, gay, bisexual
and transgender people



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This practical implementation document aims to address end of life care needs in relation to lesbian, gay, bisexual or transgender (LGBT) people, in order to improve quality of care. It has been developed following consultation with stakeholders at a series of discussion groups held around the country.

It aims to provide a practical guide for everyone working with LGBT people, and for LGBT people themselves, whether giving or receiving end of life care. This guide is an invitation to:

- Encourage LGBT people to be confident in being open about their relationships and needs
- Guide organisations and people within them to have an LGBT friendly culture and
- Highlight constructive key messages for everyone to act on.

Combining these perspectives will ensure that LGBT people and their families who experience care as an individual, partner, carer, child, friend or any other relationship/personal network, will receive high quality end of life care.

People approaching the end of life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is essential for giving people the opportunity to have a dignified death and for offering bereavement support to families and carers.

This care should be the same high quality for all and able to take account of any difference, irrespective of the person's diagnosis and setting in which they are being cared for. The key approach is one of inclusivity, therefore LGBT people and their families and carers should have access to high quality end of life care that takes account of their needs and preferences, regardless of their individual circumstances (Reference 9).

It is intended the guide will raise awareness to support practitioners and staff to develop their understanding of the unique issues faced by LGBT people, and their families and carers within our community, and how these issues impact on end of life care. This in turn will assist practitioners and staff to review and develop:

- Practice, including identification and holistic assessment of a person's needs
- Care planning
- Use of appropriate and inclusive language to facilitate understanding and identification of who is important to the individual



- The care environment to ensure it is comfortable and safe for LGBT people and their families and carers to feel able to be open.

It will also assist practitioners and staff to:

- Improve the care delivered and measure quality
- Promote positive team working and learning
- Access a range of resources and training to aid and develop practice.

This guide follows the six steps of the End of Life Care Pathway, beginning with initiating discussions as the end of life approaches and concluding with care after death.

Each section outlines relevant steps of the pathway, identifies issues to consider and links to the practitioner/staff roles. Case studies are used to highlight good practice; please note all names used have been changed to protect people's identities.

Key recommendations are included for taking this work forward and a range of further resources are highlighted. Additional guidance can be found within the 'Department of Health's End of Life Care Strategy: quality markers for end of life care' (2009) and the 'NICE quality standard for end of life care for adults' (2011) (9).

How many lesbian, gay, bisexual or transgender people are there?

Accurate numbers of people who identify as lesbian, gay, bisexual or transgender in our community are hard to establish. Questions about sexual orientation and gender identity are excluded in the census, although the Office for National Statistics (ONS) asked questions about sexual identity for the first time in 2010, as part of the Integrated Household Survey (1). Collecting this information raises some key issues:

1. Fear of discrimination can mean people are cautious about being open about sexual orientation or gender identity, so accurate statistics are difficult to achieve.
2. How people identify at the time of being asked can vary. This may be due to the wording of the question, for example 'are you lesbian, gay, bisexual or other?' Many may not feel completely aligned to any of these categories (2). Therefore this will have an impact on how comfortable an individual feels declaring their identity in this way. It is also noted that sexual orientation for some is not necessarily static throughout their lifetime and is influenced by many factors (2).

The ONS survey revealed that just under 1% identified as gay/lesbian and 0.5% as bisexual; in other words, over 750,000 adults (over 16) in the UK (1). However this figure is disputed and Treasury actuaries estimate that 6% of the population is more accurate (3), which equates to approximately 3.6 million people. However this only represents those who openly identify as L, G, B or T.

In 2009 the number of people who had sought gender reassignment treatment was estimated at 12,500, with the expectation that this figure will grow (4) as more transgender people feel able to seek increasingly available support. It is worth noting however that this figure does not represent the true extent of people who identify as transgender as there will be many who have not come forward for treatment.

The recently published Bisexuality Report (5) states that estimating the number of bisexual people is difficult due to the different definitions. What is most important is that whatever the numbers are, everyone has a right to be free from discrimination based on sexual orientation (6) and gender identity.

The LGBT acronym

One area of debate is how the numbers of bisexual and transgender men and women are represented, and whether or not estimates for the numbers of bisexual and transgender people should be merged within the overall estimates for LGBT figures.

Stakeholders agreed that whilst this integration is not ideal, it is important to include bisexual and transgender figures. The drive for this came from the stakeholder discussion groups: this is the first document to address end of life care in relation to LGBT people and stakeholders felt they would rather it be included here than not addressed at all.

However, it is important to note that lesbian, gay and bisexual labels do essentially relate to sexual orientation, whereas the term transgender is far broader and should not be confused with sexual orientation. Transgender addresses gender identity and may encompass people who are heterosexual as well as those who identify as lesbian, gay or bisexual.

The consistent message that comes from stakeholders is the reality that having a lesbian, gay, bisexual or transgender identity means living with the challenge of this difference and this can sometimes directly impact on the experience of end of life care.

It is important to note that whilst sexual orientation and gender identity is key to who people are, LGBT people will have many aspects to their identity. Further, that all care, whatever the setting and context, must take account of this to achieve high quality care for all.

The target audience for this guide is everyone working to improve end of life care services, whether commissioners, providers or recipients of health and social care.





Definitions

As previously noted, it is evident that quantifying how many LGBT people there are within our community is difficult and estimates vary; this illustrates the uncertainty that surrounds this subject and highlights the challenge and complexities of definition (2).

The research and consultation undertaken for this guide revealed there is a range of understandings of the terms lesbian, gay, bisexual and transgender, and that there are many more additional terms. Therefore definitive clarification is difficult to find and not all LGBT people openly identify with them (2). What is important is that such terms have unique meanings to the individual and the language, definitions and categories used to describe people must be considered in terms of how they impact on the person themselves (2).

Categorising people is, in itself, problematic; as one stakeholder commented, such labels “only help to hinder and create barriers”. As discussed above one criticism of the acronym LGBT is that it pulls people together as if they were similar and can mask any differences, although Price (2011) (2) claims that such lives do share some key elements such as oppression, stigma and inequality as a result of their sexual orientation and gender identity.

Price (2011) (2) also suggests that LGBT people may identify with a huge variety of definitions or labels, or none at all. This underlines how important it is to discover how the individual themselves wants to be identified.

The danger of setting definitions is there will be some who choose not to be open or do not identify with LGB or T. This could result in important differences being missed and care moving away from the person-centred approach (7). However it also is important to remember that if an individual chooses not to disclose information, that this must be respected.

This guide will use the term LGBT, although it acknowledges the difficulties of this amalgamation as if everyone is similar by virtue of membership. The recommendation that bisexuality should be treated separately (5) is acknowledged and addressed, as are those in relation to transgender issues.

The term ‘family’ will be used in its broadest sense to be inclusive of anyone the individual identifies as important in their personal network, rather than confining it to relationships determined by biology or marriage. Non-familial relationships and families of choice (8) for LGBT people are significant when receiving end of life care and for those working with them (14), therefore accurate identification of these relationships and their importance is key.

National strategy

'Equity and excellence: Liberating the NHS' (DH, 2010) set out the principle of 'no decisions about me without me', aiming to give people more choice and control over their NHS. It is intended that services become more responsive to people's needs and designed around them, rather than people having to fit around services.

The End of Life Care Strategy Equality Impact Assessment (DH, 2008a, 27) identifies sexual orientation and gender identity as the most likely area for inequality and discrimination to occur. The Strategy (DH, 2008b, 28) highlights that the nature of LGBT relationships may be concealed, with the consequence that practitioners and staff may exclude key individuals from involvement in a person's care.

The Strategy makes the critical point that high quality end of life care "should be available wherever the person may be: at home, in a care home, in hospital, a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money" (2008, 1.33, p33).

The following core principles will help to achieve the delivery of high quality end of life care:

- Care is person-centred and integrated
- Treat individuals with dignity and respect
- Communicate appropriately with compassion
- Identify and respect people's preferences
- Provide care after death.

This is supported further by the NICE quality standard for end of life care for adults (2011), which states that everyone should have access to high quality care on the basis of need, and that care needs to take account of preferences, irrespective of individual circumstances (9). These standards, detailed in Appendix 1, enable:

- Health and social care professionals to make decisions about care based on the latest evidence and best practice
- Individuals and their carers to understand what service they should expect from their health and social care provider
- Service providers to quickly and easily examine the clinical performance of their organisation and assess the standards of care they provide
- Commissioners to be confident that the services they are purchasing are high quality and cost effective.

There is a background of wider social processes that shape the experiences of a person who is LGB or T. While LGBT people and their lives vary enormously (2, 7, 10), they share a history of oppression and cultural bias in favour of opposite sex relationships (heteronormativity). In other words, health and social care workers may assume a person is heterosexual unless proven otherwise (11).

The 'unless proven otherwise' aspect often relies on the individual having the confidence to contradict the assumption that the care professional may have made, for example the assumption of asking husband or wife details as opposed to partner.





The Mental Capacity Act (2005)

For LGBT people, the Mental Capacity Act may be particularly important to pay attention to, because it allows a person to make decisions in advance of losing capacity. This can include nominating someone as a Lasting Power of Attorney, identifying who they want to share information with and who they want involved in their care. The Mental Capacity Act also provides legal redress where this does not take place.

Such decisions about wishes and preferences for care are best recorded in writing in an advance statement.

Equally, decisions need to be made throughout the end of life care pathway. The Mental Capacity Act protects those who lack capacity but also helps people to be involved in decision-making as much as possible, even as their condition deteriorates. For more guidance see Appendix 2.

The term is used widely in health and social care but lacks clear definition and does not have any formal legal status. There is a common misunderstanding that next of kin (NOK), refers to and needs to be a person related by blood or marriage.

In reality there are no rules about who can and cannot be NOK and an individual can nominate anyone in their personal network. A NOK does not have automatic rights to access medical records or have information on a person's condition. Where there is evidence that the person did not want information shared, this must be respected.

If a person has nominated a NOK prior to losing capacity then information can be discussed with them and they can provide valuable information to health and social care workers. An individual can nominate their partner, member of their family or a friend.

NOK should not to be confused with the role of 'nearest relative' under the Mental Health Act, 2007. This is a legal term, which has particular responsibilities under this Act, distinct from the nomination of NOK. (See reference 24 and 25 for further information).

Demystifying next of kin

It can be a concern for LGBT people that someone close to them will be denied visiting rights and information because they are not seen as the 'next of kin' (24). Issues of confidentiality and information sharing may arise, especially if tensions exist within the person's network as a person is approaching the end of life.

Findings from research and publications

The literature identifies a number of key issues for LGBT people; some authors place the discussion in the context of old age but many of the same issues apply across the age range in the context of end of life care. The government's ambition to maintain independence, promote social inclusion and find community-based solutions to care overlooks the reality that for some LGBT people the community in which they live may not be the 'community' with whom they identify (7).

Neville and Henrickson's study (11) found that practitioner and staff attitudes towards sexual identities influences the quality of care offered and received and that heterosexual assumptions may exist throughout care. Some LGBT people may have led a heteronormative life; that is a lifestyle as if they were heterosexual which therefore hides the true nature of their important relationships.

Older lesbian, gay or bisexual people represent a generation who lived in times when same sex relationships were

pathologised and, for gay and bisexual men, illegal. This group may have experienced incidences of prejudice (14) and therefore may be less open than younger generations.

In essence LGBT experiences can be characterised by social isolation, barriers to services and a lack of consultation (10), which in turn may be exacerbated by ageism within the LGBT community. It is also known that there are a higher proportion of lesbian, gay or bisexual elders living alone (18).

It is likely that all will anticipate or have had experience of negative reactions relating to their sexual orientation or gender identity (7). This can impact on the person's ability to have discussions about end of life care and access local community support.

The danger of the 'we treat everyone the same' approach is it fails to take account of the person's past experiences and/or anticipation of discrimination; this in itself can be a major barrier to accessing end of life care services and may actually exacerbate inequality (7).





'Coming out'

The issue of 'coming out', that is the process of telling people you are lesbian, gay, bisexual and/or transgender, is key. It may feel risky for the person to come out if they have concealed their close relationships for many years (10). The need for end of life care can mean private domestic arrangements are now subject to wider scrutiny, which can be difficult if these have not been disclosed previously. At the same time the individual may find it difficult to be open and assertive about their needs in the face of their deteriorating health and increasing dependency on others (10).

Previous disclosure of sexual orientation or transgender identity may have been traumatic. For some it could also lead to a distancing from families of origin such that the individual may rely on and prefer alternative networks of support. However, there is a risk that the significance of 'friend' relationships is not recognised before and after death. This could result in a person or group, their relationship with the dying person and their grief going unrecognised (12).

Changing care settings

Coming out is never a one off process and LGBT people may be out in some settings, though not all. Encountering new settings can require new decisions about who to tell and when about a person's sexual orientation or gender identity. Coming out at the same time as dealing with issues of ageing or a life limiting illness, in situations where LGBT people may not feel comfortable or safe to do so, can potentially lead to increasing isolation, feeling vulnerable and unsure about the reactions of others. This can happen even for people who generally feel quite confident about their identity.

Case study: Changing care settings

"The conversations are all about husbands, wives, grandchildren. If there was another gay person who I could have a little chat with and then we could both chat to the others it would be different. But on my own, I just don't feel I can join in, what can we talk about, would I be accepted?"

Barbara is an active member of a group for older LGBT people in her area. She lives in a supported housing scheme run by a housing association and is 'out' about her sexual orientation in many settings. When she first moved to her current home she didn't tell any of her neighbours because it was a new place and she didn't know anyone.

Over time she felt more confident about being able to tell them she was a lesbian but didn't know how to; as she said "do I just go down to the morning room and come out with something... and what reaction might there be, it's just scary".

The dilemma was then solved for her when her LGBT group got funding and the committee, including Barbara, were photographed for a local newspaper. Her neighbours saw the article, and overall Barbara had a positive response from them. However, she still doesn't feel comfortable using the communal space.

Case study from research project: Almack K., Exploring the delivery of services for older LGBT in supported housing and care homes. University of Nottingham. Funded by the National End of Life Care Programme (Dec 2011 to June 2012)

Social change

Many LGBT people will have lived through significant social change in terms of attitudes and legislation, such as an increase in LGBT storylines on television, equalising the age of consent for gay men (2000), the Civil Partnership Act (2004), Gender Recognition Act, (2004) and the Equality Act, (2010). An increase in Civil Partnerships has the potential to lead to new ties and inter-generational links in the future (13). Equally not all will want to register their relationship.

Many LGBT people may still face inequality and discrimination around financial affairs, pensions and registering a death. The British Social Attitudes survey (Park et al., 2008) found that a third of people surveyed took the view that homosexuality was 'always' or 'almost always' wrong. While this is an improvement on the 1987 survey when three quarters of people surveyed held these views, the recent survey does indicate that attitudes have not yet caught up with legislative changes.

Almack et al's exploratory study in 2010 (14) with older lesbian, gay or bisexual respondents identified a number of issues to address relating to end of life care. For example, older lesbian, gay or bisexual people had fewer opportunities to have children outside of heterosexual relationships or may have limited inter-generational networks.

There is recognition that personal networks grow smaller as people age, especially for those dependent on their peer group who may also be elderly (14). Older lesbian, gay or bisexual people may subsequently be more reliant on health and social care services, yet reluctant to access them for fear of discrimination.

Respondents in Almack's study reported fears of dying alone, needing carers in their own home or living in a care home alongside their heterosexual peers. All these are factors, which impact on availability of support, particularly important as a person faces, plans for and experiences end of life care.

Attitudes and values

Attitudes can be difficult to identify. The following quotes come from a survey carried out with care home staff. They provide an illustration of some possible attitudes that may be encountered and provide an opportunity to consider if you or others you work with hold similar views. They give a different perspective on the wish to treat everyone the same and highlight why we need to take account of difference. A training tool that can assist with attitudes and values training is supplied in Appendix 3, entitled 'Chris and Viv'.

"I will not laugh or treat them any differently from other residents."

"Told to go very careful with them."

"In my opinion I would be very understanding and respect people as homosexual, they are still human beings as I am."

"It doesn't matter for me if any of our residents are lesbian, gay or bisexual."

"I mean if this group does not harm anyone I'm prepared to talk with this person about sexual needs. If it may become a bigger problem I would inform my care leader or manager."

"I do think bisexuals are greedy as they can't choose who or what sex they prefer."

"Gays are great, I have a gay friend and love showing my makeup and ideas about clothes and shoes to him."

Tung Suen, Oxford Institute of Population Ageing, 'How to better meet the needs of lesbian, gay, bisexual and transgender residents in a care home setting – research project' (Age UK Oxfordshire, funded by Mental Health Foundation)

Issues for bisexual people

The Bisexuality Report (5) puts forward the key point that bisexuality should be treated separately from lesbian, gay and transgender issues for two specific reasons:

1. There is an invisibility of bisexuality because people assume the person is either gay or heterosexual and therefore bisexuality is not a 'real' identity (5,16).
2. Bisexual people encounter specific prejudice from within the lesbian, gay and heterosexual communities and this is obscured by the LGBT amalgamation (5).

Jones (2010:48) identifies a negative stereotypical view that "people who behave bisexually are often seen as greedy, promiscuous and predatory, a phenomenon which is claimed to be part of a wider biphobia" (16). Jones (2010) (16) also argues that non-mainstream relationship patterns are more common among bisexual people and this can have implications when they use health and social care services.

It is therefore important that practitioners and staff consider issues particular to those who identify as bisexual, specifically by avoiding the assumption that someone is heterosexual. If a person is currently in an opposite sex relationship, or even if they are in a same sex relationship, they may identify as bisexual.

Issues for transgender people

There are particular issues that affect transgender people. A person who has been through an element of, or has completed transition, will often refer to themselves as 'being in transition' or 'having transitioned'.

The recent Gender Recognition Act (2004) means a transgender person can apply for a gender recognition certificate, which allows the person to have a new birth certificate and be treated, for legal purposes, as a person in their acquired gender.

The Act also provides the transgender person with enhanced privacy rights which means anyone who has learnt about a person's transitioned status in an 'official capacity' (such as health and social care workers) is not able to disclose this information without the person's express permission. To share this information without permission would be a criminal offence.

A gender recognition certificate will also impact on a person's finances, for example in terms of benefits, pensions and tax entitlements which may be relevant at the end of life. It is important to recognise that a transitioned man or woman may have specific healthcare needs. Further information is available from Age UK (15). Those working with transgender people at the end of life may be unaware the person could have been a victim of hate crime as a result of their transitioned status and this could impact on their willingness to be open. Transgender people may also have been ostracised by families of origin and rely on other networks of support.

Diversity

It is important to note that all LGBT people can encounter multiple discriminations as sexual orientation and gender identity cuts across other areas of diversity in a person's life (5). Diversities to consider, taken from the Equality Act, 2010, are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. For more information see reference 20.

The key message is that understanding and openness from health and social care providers enables the individual and who is important to them to be identified as soon as possible, for assumption to be avoided and for open and safe relationships to be built.

Key recommendations from literature and stakeholders

- Do not make assumptions: that those working with LGBT people do not make assumptions about relationships and sexual orientation or gender identity if a person chooses to come out (DH, 2008a; 13, 21) (27)
- Recognise that sexual orientation and gender identity is about more than who a person has sex with: it is about a person's whole identity and a whole way of life for that individual (13).

This guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death. Each step outlines the key questions to ask about the individual's care, the practitioner's role in that care and case studies highlighting best practice.

The guide reflects the need to work collaboratively across health and social care and other care sectors in order to effectively:

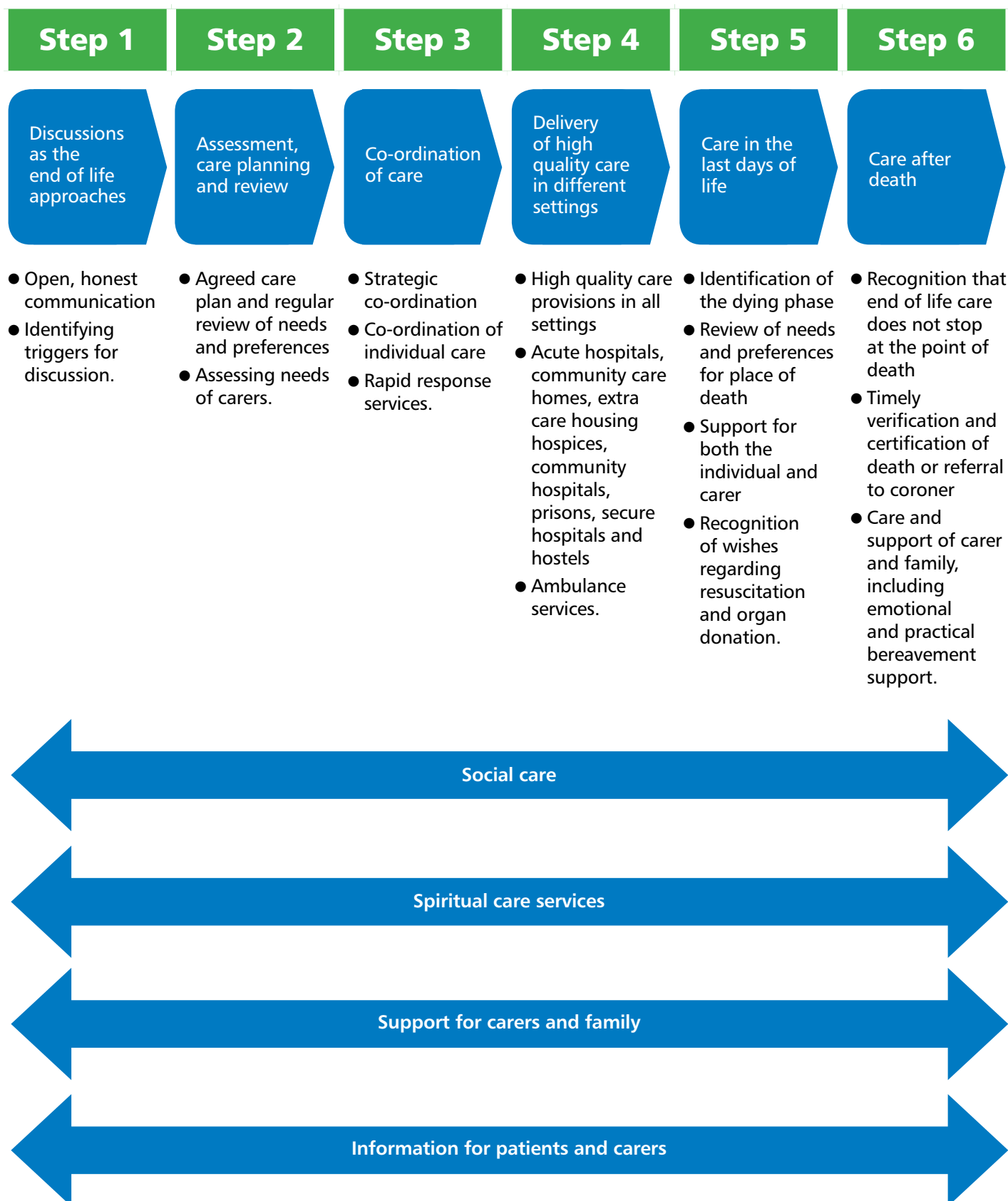
- Identify when someone is approaching the end of life and/or facing issues concerning their end of life care
- Assess needs and develop a care/support plan
- Review care/support planning
- Help to review practice and provide ways to identify and challenge any barriers to effective practice
- Support communication and team working
- Understand that in some care settings staff and other individuals may be affected by the death of a person, for example other residents, patients, service users and prisoners. It will be important to identify measures to support them appropriately.

It is difficult to predict when people are approaching the last 6-12 months of their life, but support can be sought from the more experienced workers in health and social care to improve recognition and consider the important issues that should be addressed at this time.

Providing effective, high-quality care for someone during the end of their life is challenging. Without support and information, practitioners, staff and carers can find the experience overwhelming. Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone. It may be that on initial referral no specific action is taken, but a person's future support needs and wishes may be identified and their illness progression can be monitored and reviewed when appropriate.



End of life care pathway



Step 1

Discussions as the end of life approaches

Discussions
as the
end of life
approaches

Assessment,
care
planning
and review

Co-ordination
of care

Delivery
of high
quality care
in different
settings

Care in the
last days of
life

Care after
death

Identifying when people are approaching the end of life can be difficult but it is important to do this a timely way (9). A key challenge is knowing how and when to begin discussions with an individual and their family about their wishes as they approach the end of life.

This can feel complex for LGBT people themselves, their families and those working with them. The individual and their family may feel particularly vulnerable, not only due to deterioration of health but also due the fears about their personal situation, family network and lifestyle being misunderstood or not acknowledged.

“Discussions about end of life care were complex because they were so frightened of being judged about their relationship and blamed for the illness. This fear and lack of trust meant all conversations were avoided.”

Palliative Care Nurse



Top tips

Note: These apply here but will also apply throughout all the stages of the pathway.

- Be open to different possibilities of relationships and avoid assumptions
- Identify who is important in the individual's personal network, essential for any future decisions that might need to be made in their best interests
- Consider if communication is sensitive to differences and feels comfortable. How would this question feel to you if you were asked it?
- Be open and flexible when gathering information about someone's life history, ensure clear understanding before determining needs
- Consider living arrangements, the individual may live alone and may or may not have a partner
- Avoid euphemisms/slang terms as they can be easily misunderstood
- Be aware of over imposing 'political correctness' as this could be a barrier to communication due to fear of getting it wrong
- Communicate and offer information in an accessible and sensitive way in response to an individual's needs and preferences (9)
- Ensure language is inclusive but not over-complicated, for example 'tell me who is important to you in your life'
- Be prepared to educate and support those working with you in having these difficult conversations.

Case study: A concealed diagnosis

Eric was 84 and had a diagnosis of advanced colorectal cancer. On assessment I asked for his next of kin. Reluctantly (I thought) Eric said “my friend George”.

I asked George for contact details and they both looked at each other. Eric explained in a low voice that George was his partner. Eric went on to explain it was not something they wanted to disclose but felt I should be aware. I thanked them for sharing that with me and assured them of confidentiality. Sadly Eric wept whilst George told me about the last few months.

Eric had first noticed problems four years ago but felt unable to go to the doctors. When I asked why he felt that way, Eric nervously replied “they will judge me, because I am gay”. To my astonishment it became apparent they both felt the medical profession would judge them because of their sexuality.

I sat in silence, allowing them to compose themselves; this had clearly affected them emotionally and had impacted on their relationship.

As time went on they gained confidence in me to discuss their sexuality but expressed a wish not to discuss it with anyone else. I explained that I attended weekly Gold Standard Framework meetings with their GP and Eric’s

case would arise. Eric gave consent to discuss his sexuality with one particular GP only.

Eric deteriorated very quickly; he had had his initial diagnosis but had not returned to the hospital for any follow up and had declined any treatment. We discussed Eric’s preferences for his care and together decided he should be cared for at home. Eric refused to go to a hospice or hospital as he felt again he would be judged and blamed for his disease as “self-inflicted”.

We talked at great lengths about his concerns but I was unable to ascertain whether either of them, individually or as a couple, had previously experienced any discrimination; Eric deteriorated and sadly died after only visiting for 4 weeks. He was peaceful and surrounded by those who loved and cared for him.

I found this case particularly distressing, as this couple didn’t receive adequate end of life care and support during Eric’s last few months of life. He experienced pain and other avoidable symptoms before I was involved as he was so frightened that he would be judged.

Deborah Boulden
Macmillan Clinical Nurse Specialist

Your role

- Recognise when someone’s condition has deteriorated
- Ask yourself the question ‘Would I be surprised if this person were to die in the next 6-12 months?’
- Discuss with multi-disciplinary team colleagues and select appropriate time to begin discussions
- Recognise that LGBT people may be more likely to live alone, therefore may be socially isolated and having these discussions for the first time
- Recognise the barriers that might have prevented an individual and their family from accessing services and thus having such discussions
- Recognise the potential for prejudice and acknowledge the individual may have fears about this, and the negative impact it could have on communication
- Be aware that coming out can be really difficult and may feel as if it could jeopardise the quality of care given
- Be aware that older LGBT people in particular may have historical and experiential reasons for not identifying themselves
- Recognise the full strength of friendships and their significance in a person’s support network
- An approach that conveys empathy, honesty and non-judgement and incorporates self-awareness is important
- Listening skills are paramount
- Ensure practitioners and staff have access to communication skills training to support open and honest discussions
- Provide relevant information as needed about a person’s condition, services available and finances as appropriate
- Consider cultural and spiritual aspects for the individual and their family.

Step 2

Assessment, care planning and review



An early assessment of an individual's needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as identifying any areas of unmet need. Holistic assessment needs to address physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each person.

"Accepting Vicky and Kirsty and their children as a family was the vital step in assessing their needs and planning their care. It was important to find out about the tensions in the family relationships in order to assess needs fully."

Palliative Care Nurse



Top tips

- Recognise that being open about needs and wishes can be difficult and that an honest and sensitive approach is key
- Be aware that a higher proportion LGBT people live alone and therefore may be isolated as they approach the end of life
- Identify a key worker as part of the assessment process to co-ordinate all aspects of care (9)
- Identify who in the person's personal network offers care and support; it may be important to include them in the assessment
- Establish the support needs of the carer(s) and avoid assumptions about their relationship to the person and their ability to continue caring
- If a person has a gender recognition certificate it is a criminal offence to share this information without their express permission; consider getting permission in writing
- Consider any needs related to body image, including physical appearance, that may need meeting as part of care
- Plan care and document wishes and preferences in advance of deterioration and potential loss of mental capacity
- It is important to use tools as part of care planning, such as Preferred Priorities for Care and Gold Standards Framework
- Ensure that care planning reassures the person that key people will be included when they are unable to communicate this for themselves.

Case study: A complex family dynamic

Vicky is 38 and diagnosed with advanced cancer with secondary spread. Vicky and Kirsty lived together with three children; two teenagers from Vicky's previous marriage and a baby boy conceived within the relationship using an anonymous donor.

Kirsty had health care needs that meant she couldn't drive, so the family car remained outside the house because Vicky was too weak to drive. Vicky attended the hospice day centre once a week and loved the opportunity for creativity that this gave her.

Vicky's parents were divorced and her mum helped with childcare whenever she went into hospital for treatment. Vicky also had two sisters, although they weren't closely involved. Kirsty was very close to her parents and siblings and they were supportive of the whole family.

The relationship between Vicky and her mum was fraught with tension; her mum believed Kirsty had changed Vicky and she felt uncomfortable with their relationship. This tension meant they visited separately whenever Vicky was in hospital. It was very difficult for Vicky to discuss preferences and wishes about her care with her mum because she felt it would cause an argument.

The staff at the hospice day centre were aware of these tensions and offered support to the couple and the children. They were also aware, from assessing Vicky's mum's needs, that she had concerns the children were struggling with the situation. Equally she was protective of her daughter and reluctant for her to know her worries.

The assessed needs for this family centred around the mother-daughter relationship and ensuring both Kirsty and Vicky's mum were included in care. Social isolation for them as a couple and family was key, together with financial issues as they struggled to meet the household and family costs.

Supporting the children was more difficult as Vicky's mother was very protective, but this was addressed at their pace. It was important to be fully aware of the personal network for both Vicky and Kirsty in order to clearly identify their needs. Vicky said the hospice day centre helped her to feel comfortable and accepted, free from the tension and able to make the most of her time.

Julie Bain
Registered Nurse, Hospice

Your role

- Review any discussions and decisions that took place in step 1
- Undertake a holistic needs assessment (see 'Holistic common assessment of supportive and palliative care needs for adults requiring end of life care', NEOF, 2010) (9, 22)
- Introduce advance care planning as a continuous process as early as possible
- Include key people within the person's network in the assessment; their insights will be vital to the holistic assessment
- Record wishes and preferences as an advance statement or advance decision to refuse treatment
- Ensure the advance statement is shared with the appropriate care providers and multi-disciplinary team
- Provide appropriate information in line with the person's needs and check understanding
- Be aware that people's ability to remember information may be affected by mental capacity, anxiety and general deterioration in condition
- Address any tensions relating to moving from curative to end of life care
- Advocating for the person's wishes may be central to their end of life care; it may also be helpful to consider Lasting Power of Attorney
- Develop understanding on the specific health needs of transgender men and women and your responsibilities around gender recognition
- Take account of any subtle changes reported by those closest to the individual
- Fully gather information about concerns and worries before giving appropriate information
- Ensure practitioners and staff are aware to achieve compliance
- Identify carers' needs and offer a carer's assessment if appropriate
- Provide education and training opportunities, for example free to access end of life care e-learning available via e-ELCA.

Step 3

Co-ordination of care



Once a care plan has been agreed it is important that all the services that are needed are effectively co-ordinated. This may cover primary, community and acute health providers, hospices, nursing and residential care homes and social care. Individuals should be asked for permission to share information with other services.

This is also an opportunity to establish contact details for anyone they would like to be notified if there is a change in circumstances. As in step 2, establishing who is important to the person and who offers care and support in their personal network is important.

“For me I know I don’t want my partner having to chase and worry about who is doing what. I want her to be recognised as my partner and to be well supported so we can have time together that is not fraught with uncertainty that could be avoided. Our future will be uncertain enough without lack of co-ordination adding to it.”

Member of the stakeholder group



Top tips

- Identify who is most important to the individual, for example ‘who do you want to be contacted In Case of Emergency?’
- Identify a keyworker to ensure linking between services and co-ordination of care is effective and that all contact numbers are provided
- Establish whether an advance statement, preferred priorities for care, advance decision to refuse treatment or other documentation exists, where it is held and when it was last updated
- Establish the services and people who need to know information about the individual
- Establish what kind of information is appropriate to share (noting information in step 2 regarding gender recognition)
- Consider the pressure on the individual and the family if this means coming out to lots of providers of care
- It is important for care providers to avoid assumption about relationships that are significant to the person
- A person’s support network may consist of peers who are also in poor health and therefore unable to offer support
- Avoid assuming that someone is heterosexual or homosexual based on their current relationship; they may identify as bisexual
- Recognise the increasing diversity of all family relationships, whether heterosexual or LGBT relationships.

Case study: A different family network

Joan married young but found she was unable to have children. She and her husband separated and later divorced. Joan had a couple of relationships, one with a woman and one with a man and started to identify as bisexual.

In her late forties Joan met a woman, Margaret, who already identified as a lesbian. Joan was strongly attracted to her and they started a relationship. Margaret was younger than Joan and had a daughter, Tracey, who lived with them. Joan was fully involved in Tracey's life and became part of Margaret's circle of friends in their local lesbian scene.

Although Joan still identified as bisexual many people saw her as a lesbian. Labels were not particularly important to her and so she did not challenge this. After many years together, Joan and Margaret split up and about a year later Joan started a new relationship with a man, Richard. Many of her friends from the social circle she had shared with Margaret disapproved of this relationship and she was left feeling quite isolated.

Recently, Joan experienced some major health problems and now requires care services at home. Joan has no close family. She and Richard are still together but live separately. Margaret's daughter Tracey continues to have a close relationship with her, she thinks of her as her second mum and often calls her 'mum'. Joan also maintained a friendly relationship with her ex-partner Margaret and they have increasingly supported each other as they have aged and both live alone.

Adapted from a case study reported in Jones (2010) (16). Jones developed a series of case studies based on the findings of a variety of research studies and also on real life situations known to members of the UK bisexual community.

Your role

- Ensure that wishes and preferences are clear and can be understood
- Ensure communication systems are in place and clear with all service providers and identify the key contacts across all organisations
- Check whether the person is on the Supportive Care Register or an electronic palliative care co-ordination system (EPaCCS)
- Provide access to 24/7 advice, support and urgent care including medicines and equipment in the event of a crisis, day or night (9)
- Refer to specialist palliative care, appropriate to a person's needs and preferences (9)
- Inform out of hours services of any anticipated needs and provide the individual and their family with essential contacts
- Facilitate/utilise anticipatory prescribing as appropriate
- Offer support for social, practical and emotional needs, appropriate to preferences, to maximise independence and social participation (9); this could include finding out about LGBT services in the local area
- Be aware of the complexity of relationships and the difficulty in explaining them to carers or having to do so multiple times
- Be aware that the person and their family may have encountered homophobia/biphobia/transphobia or expect to do so when meeting care providers for the first time
- Be aware a person may 'depersonalise' their home, for example take down photographs, to ensure feeling safe from discrimination and hostility when encountering a variety of care providers
- Be aware there may be a need to provide support for people to lead their lives as they choose; this could include contact with other LGBT people
- Promote acceptance of all relationships and provide learning opportunities for colleagues about equality and diversity, which includes issues relating to LGBT people.

Step 4

Delivery of high quality services in different settings

Discussions as the end of life approaches

Assessment, care planning and review

Co-ordination of care

Delivery of high quality care in different settings

Care in the last days of life

Care after death

In the last year of life, individuals and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of where they are being looked after.

LGBT people and their families want to be treated with dignity and respect and given as much choice as possible about care as they approach the end of their lives.

"I visited my elderly aunt in a care home and I decided to tell her I was going to go through transition. What I didn't expect was that she would be on the receiving end of ridicule and micky-taking about me. This was happening after each visit and it made things really tough and upsetting."

Member of the stakeholder group



Top tips

- Ensure the environment and organisational literature conveys images that support a range of family situations, portraying a variety of relationships, including same-sex relationships
- Review organisational mission statement and core values to ensure these are inclusive and person-centred
- Practitioners and staff may need support to bring about change
- Collaborate with other providers to share good practice and identify models of practice
- Identify a measured response to environmental changes, it may be that acknowledgement of difference is more appropriate than high profile messages
- Positively challenge poor practice and embed awareness with education and training to ensure a learning culture is promoted
- Be aware that individuals and their families can encounter multiple providers of care at the end of life
- Promote open and honest communication
- Involve LGBT people in reviewing end of life care services.

Your role

- Develop or be aware of a policy for end of life care in your care setting
- Ensure all staff are aware of and understand the core principles of end of life care and values
- Promote or participate in end of life care training, including communication skills, assessment and care planning, advance care planning, symptom management and ensuring comfort and well-being
- Ensure due consideration is given to the environment in which end of life care is delivered
- Engage LGBT people and organisations in the process on continuous service improvement
- Develop links with other care providers to develop practice.



Case study: Experiences within a nursing home

Anna's Aunt Mary was being cared for in a nursing home. Anna was a regular visitor and well known to residents and staff. Whilst Mary's health was deteriorating, Anna, after many years of internal struggle, had made the decision to undergo full gender reassignment, which meant hormone treatment and major surgery.

It was at this time of her transition that Anna understood the need to tell her aunt, and this story illustrates some of the challenges and how they were addressed.

Anna told Mary she was undergoing treatment to become a woman. Mary responded positively to this news, so much so that when Anna visited subsequently, Mary would introduce her to other residents and staff as 'my new niece'. As Anna had now begun transition, this meant she was living and dressing as female, including her visits to Mary.

The challenges evolved around the reactions of others; many residents and staff would make comments once Anna had left, sometimes directly to Mary or indirectly, but still within earshot or sight. These hurtful remarks and ridicule left Mary feeling very distressed and were noticed by her carer who eventually spoke to Mary about it.

Mary chose not to speak to Anna about it, but recognised the insults had to be addressed and stopped. In spite of the difficulties Mary never stopped introducing Anna as 'my new niece'.

Once the carer and social worker were aware of the situation they responded positively and spoke to Anna immediately to inform her of the insults and ridicule. The staff committed time to do some reading so they understood more about gender reassignment and the support Anna may need as she went through transition and cared for her aged aunt.

Anna felt shocked and was devastated by the news, as it wasn't something she had expected, but she was also very impressed by the support and action of the staff. As intended they did increase their understanding, the issue of ridicule and comment was addressed and stopped and Anna was consistently treated with respect.

Sadly Mary died some while later when Anna was in hospital having her first operation, but she was comfortable, well cared for and content the comments and ridicule had stopped. The whole experience has left Anna certain that she needed to be supported in a respectful way that accounted for her difference. Anna is also certain that if she ever needed to be cared for in a nursing home at the end of her life, then she would choose the same home as Aunt Mary.

Anna May Booth
Member of the stakeholder group

Step 5

Care in the last days of life

Discussions
as the
end of life
approaches

Assessment,
care
planning
and review

Co-ordination
of care

Delivery
of high
quality care
in different
settings

Care in the
last days of
life

Care after
death

A time comes when an individual enters the dying phase. For some this may appear to happen suddenly and without warning but for many others it can be a gradual process.

It is vital that those caring for them recognise when a person is dying and take the appropriate action, including delivering co-ordinated care in accordance with their personalised care plan and rapid access to care if needed (9). How someone dies remains a lasting memory for the individual's relatives, friends and the health and social care staff involved.

"An inclusive approach captures everyone who is important to that person, takes account of individuality and ensures no one is excluded."

Chaplain



Top tips

- Ensure that communication continues to be open now the person is dying
- Clarify the level of information that people want as this may have changed as the person deteriorates
- Recognise discussions about wishes and preferences may have already taken place, but some may not have had the opportunity
- Check if any wishes have changed and ensure care is still tailored to needs; place of death may be part of this but ensure plans are realistic
- Recognise support needs of friends/carers/family; consider how relationships are being affected by the dying process
- Support those working with the individual and their family, especially in the recognition of dying and communication skills
- Identify and address any spiritual and religious needs (9)
- Identify who the person wants present at the bedside and facilitate where possible
- Be aware there may be conflicts of interest between people involved, such as those closest to the person and members of their family of origin
- Be open to specific requests; the individual may want a wide group of friends with them or particular items of significance.

Case study: An inclusive approach

Grant is a 40 year old gay man, diagnosed with a brain tumour. He was in a Civil Partnership with Michael. When curative treatment options ended Grant was referred to the hospice for palliative care.

Within Grant's family, relationships were strained. His mother, Denise, who lived some distance away, struggled with Grant's sexuality and his relationship with Michael. Michael struggled with his need to continue working and caring for Grant.

Grant was supported by the homecare service and social work support was also offered. Grant took advantage of the complementary therapy service, but he was reluctant to access the hospice day care facilities.

Eventually, Grant was admitted to the hospice as his condition deteriorated. Admission to the hospice meant that family relationships previously managed at a distance, became strained on the ward. Grant's mother, Denise, and Michael did not communicate easily. This tension affected Grant's care as staff members were approached by Michael and Denise separately seeking information and reassurance.

Social work support was offered to the whole family, but refused by Denise. The social worker involved ensured staff members were supported in listening to both Michael and Denise who were finding it difficult to be present with Grant together. Michael's status as Grant's civil partner was reinforced, but Denise's role, as Grant's mother was respected and her questions answered honestly.

The Chaplain was asked to see Grant to help make funeral arrangements. He wanted a service in his local Church of England church, but was concerned that the vicar would refuse. Liaison between the Chaplain and the local vicar resulted in agreement the service could be held at the Church and at Grant's request, joint planning of the funeral continued.

Denise held a conservative Christian faith, although she was not practising. She was pleased Grant was in contact with the Chaplain, but could not voice her spiritual needs or distress until Grant was dying, when she asked for prayers to be said. This request was checked out with Michael, who agreed and was present.

Throughout Grant's hospice journey, staff ensured his needs were paramount and that familial relationships were recognised and respected. When possible, Grant was consulted before information was given and at ward rounds family members present were included in conversations in Grant's room. Staff supported Grant and his family, ensuring no one felt excluded.

Many families have complex needs. The approach taken with Grant and his family mirrors that which is taken with each person in the hospice.

Rev Andrew Goodhead
Spiritual Care Lead

Your role

- Use a validated integrated care pathway for care in the last few days, such as the Liverpool Care Pathway
- Be aware that using a care pathway does not hasten or postpone death; occasionally a person's condition may improve and the pathway can be discontinued
- Ensure anticipatory prescribing is in place in advance of need
- Identify any concerns friends and family may have and provide information appropriately, sensitively and honestly so they know what to expect in the last few days
- Ensure where possible that a person's preferences and wishes are met
- Be aware that the person's partner may be their main carer and feel loss of the partnership; support them in restoring that part of the relationship if possible
- Ensure that care is inclusive and offers support to all involved, regardless of tensions
- Ensure practitioners and staff remain impartial if there is family conflict but recognise difficulties and support all concerned.

Step 6

Care after death



Good end of life care doesn't stop at the point of death. When someone dies, practitioners and staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support provided to staff, friends and relatives will help them cope with their loss and is essential to achieving a 'good death'.

"Respecting the person and ensuring care is dignified whilst allowing for individuality to be expressed applies after death as well as before. High quality care after death continues the care that has happened before."

District Nurse

'Risk factors', in other words characteristics of the bereaved person and their situation, may identify increased vulnerability and may benefit from referral to bereavement services. For LGBT people there is a risk that the significance of their relationship to a deceased partner is not fully acknowledged by all parties and their grief goes unrecognised. Many may also have relationships where it is difficult to explain the full extent of what that relationship is or meant; that might particularly be the case for bisexual and transgender people as well as for lesbians and gay men.

For LGBT people, issues may therefore include increased social isolation due to fear of 'being outed' or 'coming out' because of their relationship with the deceased, and isolation from their support network which may consist of peers rather than the local community of place.

Family and friendship groups may be a source of support but may also be a source of tension, and this affects the support available to the bereaved person (Relf et al., 2010) (see reference 17 and 19). These factors will impact on the degree of vulnerability and need for further support, and sit alongside those issues that are usually associated with the death of a partner or loved one.

"Care after death should be a positive experience, no matter who you are or how you die"

Funeral Director

Top tips

- Recognise that wishes may have been discussed with the individual and those important to them before their death
- Clarify the wishes of the family in terms of viewing the body and ensure this fits with any wishes the person who has died may have stated
- Give opportunity for everyone affected to acknowledge the death and consider everyone's support needs; recognise the strength of 'friend' relationships to ensure grief is not overlooked
- Offer verification and certification of death in a timely manner (9)
- If an employer, review criteria for staff's compassionate leave to ensure equality
- Know your limits and when to refer on – be compassionate to yourself
- Continuity helps avoid people having to establish new relationships at the bereavement stage: take a case-by-case approach and be aware of who has the relationship with different members of the family
- Recognise that some may need additional support; offer practical support and signpost for the next steps after death
- Advise people about the National Bereavement Survey (VOICES) and use results from it to give staff feedback and support continuous improvement.



Case study: Unrecognised grief

Individuals may have reasons for choosing not to disclose a loving, close, same sex relationship. Not being 'out' can have huge implications for couples in same sex relationships when one partner dies.

Jeremy and his partner David had not disclosed their relationship to anyone. Jeremy said David had been very clear they could not be open about their relationship. When David died his family made the funeral arrangements in which Jeremy had no say:

"I knew he wanted burial and he wanted to be buried next to his mother. He ended up being cremated the other side of (city) and cremation was totally against his religion... I couldn't stop them but it was like strangers organising his funeral; I was his family... But he never wanted it to be known that he was gay. And I respected that, so he wasn't out, I wasn't out then either. I couldn't talk to my family... they thought David was just a friend. I was a right mess. I had no-one to turn to."

Another gay man, Michael, recalls a friend who did not get compassionate leave when his partner died and very little recognition of his loss other than from close friends:

"I went to his funeral and the family were none too happy with the situation, I don't think they wanted people knowing their son, brother was gay. And my friend who was grieving, he's been with his partner for years, he never got a mention from the vicar, not one."

The significance of Jeremy's loss and grief is not only not recognised and validated but further complicated by the absence of personal networks where he may have found support and by David's family taking over. In the second case, Michael describes how his friend, the bereaved partner, receives some recognition from friends but none from his partner's family who refuse to acknowledge the relationship.

Case studies taken from Almack et al, (2010) (14)

Your role

- Care for the body of a person in a dignified and culturally sensitive way (9)
- Respect individual relationships, faiths and beliefs and take steps to meet their requirements
- Be aware of verification and certification of death policies and develop them if not in place
- Ensure key people closest to the deceased are involved in care immediately after death, if they wish to be
- Provide information to the relevant people about the next steps and ensure the correct person receives the death certificate
- Offer information on bereavement support or consider need for referral as appropriate and in accordance with their preferences (9)
- Ask for specialist advice to discuss bereavement needs assessment if necessary (17)
- Offer practitioners and staff the opportunity for debriefing after a death
- Provide a comfortable environment for practitioners and staff to discuss and share their concerns.

Many of the issues and challenges occurring at different stages along the end of life care pathway for LGBT people call for a co-ordinated and collaborative response. The following key levers have been identified as a useful basis for developing local, regional and national action plans. They are informed by the actions identified in End of Life Care Strategy Equality Impact Assessment (DH, 2008a) (27).

Some levers apply at an individual level:

- Developing practice through education and training to positively address communication skills and attitudes. All staff should undertake relevant training in equality and diversity, confidentiality and the Mental Capacity Act, and should keep up to date on current equality legislation.
- Raising awareness of unique issues faced by LGBT people, their family and carers and how this impacts on end of life care. It should be recognised that the 'treat everybody the same' approach can sometimes exacerbate inequality.
- Identifying opportunities to encourage active involvement at all steps along the pathway.
- Promoting inclusive language so as not to inadvertently make someone feel as if they must reveal their sexual orientation and gender identity. Certain phrases promote greater inclusivity, such as "who are the most important people in your life?", as opposed to spouse or next of kin.

Levers at a structural or strategic level include:

- Promoting equality and diversity to ensure high quality care for all that takes account of difference, regardless of individual circumstances, and recognises that many LGBT people still face inequality and discrimination.
- Promoting a positive learning culture so that instances of care can be reflected on and learnt from.
- Positively marketing care homes, hospices and extra care housing as LGBT friendly so that positive messages are conveyed and LGBT people feel welcomed in these environments. Reporting of any discrimination by staff or other residents must be positively encouraged.
- Closer partnership working among all stakeholders to ensure LGBT people are involved in service review and development and that models of good practice are shared.
- Promoting openness to all relationships from health and social care providers to avoid assumptions about sexual orientation, gender identity and relationships, and explore this sensitively with the person. In turn, this enables the individual and who is important to them to be identified as soon as possible and for open and safe relationships to be built.
- Having a clear policy on confidentiality which includes how a situation is handled if a person comes out and how / if the person wants this included it in their care plan.



e-ELCA e-learning

Free to access for health and social care staff and includes over 150 modules covering advance care planning, assessment, communications skills, symptom management, integrated learning, social care, bereavement and spirituality:

www.e-lfh.org.uk/projects/e-elca/index.html

Macmillan Learn Zone

Provides a wide variety of online resources, cancer specific e-learning programmes and professional development tools, including an out of hours toolkit:

www.macmillan.org.uk/learnzone

Developing end of life care practice

A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care:

www.endoflifecareforadults.nhs.uk/publications/corecompetencesframework

Critical success factors that enable individuals to die in their preferred place of death

This report identifies the critical success factors associated with improving end of life care and enabling a person to die in the place of their choice:

www.endoflifecareforadults.nhs.uk/publications/critical-success-factors

The End of Life Care Quality Assessment tool (ELCQuA)

An online tool to monitor and compare end of life care services with similar organisations locally and nationally. Progress can be assessed against a set of core specifications based on the Department of Health's quality markers and measures for end of life care:

www.elcqua.nhs.uk

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network aims to improve the collection and analysis of information about end of life care services. This intelligence will help drive improvements in the quality and productivity of services:

www.endoflifecare-intelligence.org.uk

Gold Standards Framework Prognostic Indicator Guidance

Clinical prognostic indicators are an attempt to estimate when people have advanced disease or are in the last year or so of life. This indicates to health and social care professionals that people may be in need of palliative/supportive care:

www.goldstandardsframework.org.uk

Mental Capacity Act Code of Practice

The Code of Practice supports the Act and provides guidance to all those who care for and/or make decisions on behalf of adults who lack capacity. It includes case studies and clearly explains in more detail the key features of the Act:

www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

Best interests at end of life

This practical guidance is intended to assist those supporting people who lack capacity to make their own decisions:

www.endoflifecareforadults.nhs.uk/publications/bestinterestseolguide

Planning for your future care

Aimed at members of the public, this guide explains advance care planning and outlines the different options available to people. It is available in English, Arabic, Bengali, Chinese (Mandarin), Polish, Punjabi and Urdu:

www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

I didn't want that

Dying Matters created this short film to highlight the importance of people making their end of life wishes clear:

www.dyingmatters.org/page/i-didnt-want-that

Making a will

Advice from the Citizen's Advice Bureau on making a will, detailing what to include and keeping it up to date:

www.direct.gov.uk/en/governmentcitizensandrights/death/preparation/dg_10029800

Capacity, care planning and advance care planning in life limiting illness

This guide covers the importance of assessing capacity to make particular decisions about care and treatment, and of acting in the best interests of those lacking capacity:

www.endoflifecareforadults.nhs.uk/publications/pubacpguide

Advance decisions to refuse treatment

A guide to help understand and implement the law relating to advance decisions to refuse treatment:

www.endoflifecareforadults.nhs.uk/publications/pubadrtguide and www.adrt.nhs.uk

Preferred Priorities for Care (PPC) tools

PPC is a person-held document which was designed to facilitate individual choice in relation to end of life care. Tools are available including documentation, an easy-read version, leaflet, poster and support sheet:

www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

Electronic Palliative Care Co-ordination Systems (EPaCCS)

Formerly known as end of life care locality registers, EPaCCS enable the recording and sharing of key information about an individual at the end of their life, their care and preferences. More information on the core content that is to be recorded in such systems is available at:

www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-careinformation-standard

The route to success in end of life care series

These National End of Life Care Programme publications aim to provide practical support and guidance for health and social care professionals responsible for delivering end of life care. The publications cover:

- Care homes (June 2010)
- Acute hospitals (June 2010)
- Hostels and homeless people (Dec 2010)
- People with learning disabilities (Feb 2011)
- Domiciliary care (Feb 2011)
- Occupational therapy (June 2011)
- Nursing (July 2011)
- Environments of care (Aug 2011)
- Prisons (Sept 2011)
- Ambulance services (Feb 2012)
- Lesbian, gay, bisexual and transgender people (June 2012)
- Social work (July 2012)

www.endoflifecareforadults.nhs.uk/tools/core-tools/rtsresourcepage

Living and dying with dignity

This best practice guide for the provision of end of life care for people with a learning disability offers help and guidance to health and social care professionals, service developers and providers:

www.mencap.org.uk/all-about-learning-disability/information-professionals/health/end-life-care

Can you see me?

This National Council for Palliative Care film aims to encourage providers and commissioners of end of life care to consider everyone in their community. It focuses on the needs of people who are often invisible and describes how to respond and ways to ask people what they want:

www.ncpc.org.uk

Open to all?

This report and DVD from the National Council for Palliative Care highlights the importance of meeting the end of life care needs of LGBT people appropriately and sensitively:

www.ncpc.org.uk/library

The Liverpool Care Pathway for the Dying Patient (LCP)

The Liverpool Care Pathway is a multi-professional, outcome driven document that provides an evidence-based framework for the delivery of care during the last days or hours of life:

www.mcpcil.org.uk/liverpool-care-pathway/

Guidance for staff responsible for care after death (last offices)

This publication emphasises that the care extends well beyond physically preparing the body for transfer. It also covers privacy and dignity, spiritual and cultural wishes, organ and tissue donation, health and safety and death certification procedures:

www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death

When a person dies: guidance for professionals on developing bereavement services

This covers the principles of bereavement services and guidance on workforce education and the commissioning and quality outcomes of bereavement care:

www.endoflifecareforadults.nhs.uk/publications/when-a-person-dies

Appendix 1: NICE quality standard for end of life care for adults

In November 2011 NICE published a Quality Standard for end of life care which contains 16 statements:

1. People approaching the end of life are identified in a timely way.
2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. Families and carers of people who have died receive timely verification and certification of the death.
14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

More information on the Quality Standard can be found at:

www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp

In December 2011, NICE also published commissioning guidance to support the Quality Standard:

www.nice.org.uk/usingguidance/commissioningguides/endoflifecare/endoflifecareadults.jsp

Appendix 2: Mental Capacity Act (2005) support sheet

The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

The five statutory principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

How should people be helped to make their own decisions?

To help someone make a decision for themselves, check the following points:

Providing relevant information

- Does the person have all the relevant information they need to make a particular decision?
- If they have a choice, have they been given information on all the alternatives?

Communicating in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand, for example, by using simple language or visual aids?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication, for example, a family member, support worker, interpreter, speech and language therapist or advocate?

Assessing Capacity

Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:

- Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? It doesn't matter whether the impairment or disturbance is temporary or permanent.

- If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

Assessing ability to make a decision

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision, by talking, using sign language or any other means? Would the services of a professional, such as a speech and language therapist, be helpful?

Assessing capacity to make more complex or serious decisions

- Is there a need for a more thorough assessment, perhaps by involving a doctor or other professional expert?

Compiled by Julie Foster, End of Life Care Lead at the Cumbria and Lancashire End of Life Care Network

Appendix 3: A training tool to help address attitudes and values

This tool can be used as an exercise as part of wider learning. By the end of the exercise participants will be able to:

- Recognise assumptions that can be made about sexual orientation and gender identity
- Identify the impact this may have on LGBT people and the care given
- Consider how practice in the workplace could be developed

It may be useful to establish ground rules for the group to ensure that different opinions are safe to express, listened to and respected.

Ask participants to read individually, to take time to form their own opinion and to complete the question grid. Participants can then discuss their answers in pairs and with the whole group, addressing impact on the person and identifying alternatives in practice.

Chris and Viv

Chris and Viv walked down the street holding hands. They were very close and even though they were only sixteen, they were sure they loved each other. "It's not fair Chris," said Viv, "your parents give you such an easy time, why don't mine?"

Viv's parents were strict and expected to be obeyed. Viv wanted to finish school and become a nurse but at times it all seemed too much. It was only Chris's support that kept Viv going.

For Chris, things were different. Chris planned to finish school, become an apprentice and work hard to do well. With parents who thought those plans were fine and expected their children to be responsible for their own decisions and lives, Chris felt really lucky.

It was sometimes hard to understand why they felt so attracted to each other, as they came from such different backgrounds.

You have just read the story of Chris and Viv. Please work alone to answer the following questions by ticking the most appropriate response.

Statements about the story	True	False	Don't know
Viv is a girl			
Viv does well at school			
Chris is a boy			
Chris wants to be a mechanic			
Viv and Chris are in love			
Viv and Chris plan to become engaged			
Viv and Chris are sleeping together			
Viv's parents want to keep them apart			
Viv and Chris are from different cultures			
Viv and Chris are both girls			
Viv and Chris are both boys			
Chris's parents support their children's decisions			
Viv wants to be a nurse			

1. Measuring Sexual Identity: Evaluation Report, Office for National Statistics (2010).
www.ons.gov.uk/ons/rel/ethnicity/measuring-sexual-identity---evaluation-report/2010/index.html
Date last accessed: 20th April 2012
2. Price, E (2011) LGBT sexualities in social care research. Available from:
www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR_Methods_Review_2.pdf
Date last accessed 28th April 2012
3. Submission by Stonewall (SC-68) to Speaker's Conference on Parliamentary Representation, Parliament UK (2009).
Available from:
www.publications.parliament.uk/pa/spconf/167/167we78.htm
Date last accessed: 27th April 2012
4. Reed B., Rhodes S., Schofield P., Wylie K., (2009) Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution; Gender Identity Research and Education Society.
Available from:
www.gires.org.uk/assets/Medpro-Assets/GenderVarianceUK-report.pdf
Date last accessed: 28th April 2012
5. Barker M., Richards C., Jones R., Bowes-Catton H., Plowman T., Yockney J., Morgan M., (2012) The Bisexuality Report: Bisexual inclusion in LGBT equality and diversity, The Open University.
Available from:
www8.open.ac.uk/ccig/files/ccig/The%20BisexualityReport%20Feb.2012.pdf
Date last accessed: 28th April 2012
6. Ford, Z (2011) Just how many gay people are there and does it matter?
Available from:
<http://thinkprogress.org/lgbt/2011/05/31/231402/just-how-many-gay-people-are-there-and-does-it-matter/>
Date last accessed: 28th April 2012
7. Cronin A., Ward R., Pugh S., King A., Price E., (2011) Categories and their consequences: Understanding and supporting the caring relationships of older lesbian, gay and bisexual people, *International Social Work*, 54(3), 421-435
8. Weeks J., Heaphy B., Donovan C., (2001) *Same Sex Intimacies: Families of choice and other life experiments*, London and New York: Routledge
9. NICE (2011) Quality standard for end of life care for adults: Equality and diversity considerations. Available from:
www.nice.org.uk/guidance/qualitystandards/endoflifecare/EqualityAndDiversityConsiderations.jsp
Date last accessed: 29th April 2012
10. Almack K., (2007) End-of-Life Needs of Lesbian, Gay and Bisexual Older People, *End of Life Care*, Vol 1 (2), 27-32
11. Neville S., Henrickson M., (2006) Perceptions of lesbian, gay and bisexual people of primary healthcare services, *Journal of Advanced Nursing*, 55 (4), 407-415
12. Doka K., (1989) *Disenfranchised Grief*, Lexington, MA: Lexington Books
13. Knocker S., (2006) *The whole of me... Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing*, London: Age Concern
14. Almack K., Seymour J., Bellamy G., (2010) Exploring the Impact of Sexual Orientation on Experiences and Concerns about End of Life care on Bereavement for Lesbian, Gay and Bisexual Older People, *Sociology*, 44 (5): 908-924
15. Age UK (2011) Transgender issues in later life. Available from:
www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS16_Transgender_issues_in_later_life_fcs.pdf
Date last accessed: 29th April 2012
16. Jones, Rebecca L. (2010). Troubles with bisexuality in health and social care. In: Jones, Rebecca L. and Ward, Richard eds. *LGBT Issues: Looking beyond Categories. Policy and Practice in Health and Social Care* (10). Edinburgh: Dunedin Academic Press, pp. 42-55.

17. Relf M., Machin L., Archer N., (2010) Guidance for bereavement needs assessment in palliative care, second edition, Hoddesdon UK: Help the Hospices
18. Heaphy B, Yip AKT, Thompson D (2002) The Social and Policy Implications of Non-heterosexual Aging, Economic and Social Research Council.
Available from:
www.esrcsocietytoday.ac.uk
Date last accessed: 26th April 2012
19. Department of Health, (2007) Bereavement: A guide for Transsexual, Transgender people and their loved ones.
Available from:
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074251.pdf
Date last accessed: 7th May 2012
20. Equality Act (2010) Home Office.
Available from:
www.homeoffice.gov.uk/equalities/equality-act/
Date last accessed: 7th May 2012
21. Commission for social care inspection (March 2008), Putting people first: Equality and Diversity Matters - Providing appropriate services for lesbian, gay and bisexual and transgender people.
Available from:
http://archive.cqc.org.uk/_db/_documents/putting_people_first_equality_and_diversity_matters_1_large_print.pdf
Date last accessed: 8th May 2012
22. National End of Life Care Programme (2010) Holistic common assessment of supportive and palliative care needs for adults requiring end of life care.
Available from:
www.endoflifecareforadults.nhs.uk/publications/holisticcommonassessment
Date last accessed: 8th May 2012
23. Rogers E., (2012) Out of the Shadows, Inside Housing. co.uk.
Available from:
www.insidehousing.co.uk/tenancies/out-of-the-shadows/6520609.article?sm=6520609
Date last accessed: 11th May 2012
24. Royal College of Nursing and Unison, Not 'just' a friend: best practice guidance on health care for lesbian, gay and bisexual service users and their families.
Available from:
www.unison.org.uk/acrobat/14029.pdf
Date last accessed: 11th May 2012
25. British Medical Association (2008) Mental Capacity Act tool kit.
Available from:
www.bma.org.uk/images/MentalCapacityToolKit%20July2008_tcm41-175571.pdf
Date last accessed: 11th May 2012
26. Park, A., J. Curtice, K. Thomson et al. (2008) British Social Attitudes, the 24th Report. London: Sage
27. Department of Health (2008a) End of Life Care Strategy: Promoting high quality care for all adults at the end of life. Equality Impact Assessment.
Available from:
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086272.pdf
Date last accessed: 26th April 2012
28. Department of Health (2008b) End of Life Care Strategy: Promoting high quality care for all adults at the end of life.
Available from:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
Date last accessed: 26th April 2012

This guide has been developed by the National End of Life Care Programme as part of its series *The route to success in end of life care*. It has been developed in partnership with Bridget Moss (lead author), Director of Education at St Helena Hospice, Colchester, in consultation with Tes Smith, Social Care Lead at the National End of Life Care Programme and Kathryn Almack, Senior Research Fellow at the University of Nottingham.

The guide has also had input from various individuals and organisations. This includes consultations with stakeholders via a series of discussion groups held around the country. Organised by the University of Nottingham, the National End of Life Care Programme and the National Council for Palliative Care, the events were aimed at LGBT people and those who work with them. The stakeholders who attended gave rich and diverse views and their recommendations have been integrated into this guide.

Special thanks go to:

- All individuals who gave their time to participate in events across the country
- Individuals from the LGBT stakeholder group who have contributed to the case study material
- All who have contributed to the good practice examples and top tips that make this guide a practical resource
- Colleagues from all care sectors who have given their thoughts and opinions, which has informed this guide
- All who have commented and provided insightful feedback on the draft versions of the guide.

www.endoflifecareforadults.nhs.uk

Published by the National End of Life Care Programme

ISBN: 978 1 908874 29 0

Programme Ref: PB0041 A 06 12

Publication date: June 2012

Review date: June 2014

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